Copyright @ 2016 , Zelwietro, S.

Critical Review:

What are the factors that contribute to patient non-compliance of SLP swallowing recommendations in the treatment of dysphagia?

Siobhan Zelwietro
M.Cl.Sc SLP Candidate
University of Western Ontario: School of Communication Sciences and Disorders

This critical review examined the current literature regarding the possible reasons for clients' non-compliance with dysphagia treatment recommendations made by Speech-Language Pathologists. Five research studies were retrieved on the topic that met criteria for inclusion. Researchers examined the possible factors responsible for non-compliance through a variety of research methods. Overall, a variety of factors that play a role in compliance were identified, including feelings of denial, quality of life concerns, recommendations omitted from discharge reports, lack of education and training (of both professionals and patients), and time limitations. Recommendations for future research and clinical practice are provided.

Introduction

Dysphagia is the term given to swallowing difficulties stemming from a variety of aetiologies (Kaizer, Spiridigliozzi, & Hunt, 2012). In order to improve patients' abilities to safely consume food and drink without increasing the risk of aspiration and/or aspiration pneumonia due to unmanaged dysphagia (Lim, Mulkerrin, Mulkerrin, & O'Keeffe, 2016), Speech Language Pathologists (SLPs) assess individuals' swallowing capabilities and then make clinical recommendations (Jackson, Little, Kung, Williams, Siemiatkowska, & Plowman, 2008). These recommendations can include modifying how the patient eats and swallows (e.g. posture modifications) and/or what the patient eats (e.g. thickened liquids) (Kind, Anderson, Hind, Robbins, & Smith, 2011). These recommendations may result in safer eating, but may also be associated with an overall decrease in quality of life, leading many patients to become non-compliant with these recommendations (Colodny, 2005).

I am interested in exploring the factors associated with non-compliance of SLP recommendations made for the management of dysphagia. In addition, the clinical implications of these findings will be discussed, and future areas of research will be suggested.

Objectives

The primary objective of this review is to identify factors associated with non-compliance of SLP recommendations for the management of swallowing difficulties and to provide a critical appraisal of the identified literature.

The secondary objective is to provide suggestions of what might be done to address these factors in clinical practice and to possibly increase the rate of compliance with dysphagia recommendations.

Methods

Search Strategy

Originally the following search terms were entered into Google Scholar: swallowing, dysphagia, "Speech Language Pathology", "quality of life". From there the Western Libraries website was utilized to access the online database SCOPUS. The same search was repeated. Results were limited to peer-reviewed English-language journal articles published within the last 15 years. Once articles were found discussing 'non-compliance' this term was also added to the search, and results were narrowed down.

Selection Criteria

Papers that did not address possible factors associated with non-compliance were excluded. Articles to be included focused on 1) the reasons why a patient would not comply with recommendations and 2) problem-solving solutions to non-compliance, either with the patients themselves or with healthcare professionals working in the field.

Data Collection

Using the above search terms, five articles identified met the inclusion criteria. The studies reviewed include a retrospective cohort study (Kind, Anderson, Hind,

Robbins, & Smith, 2011), a blocked group randomization trial design (Lim, Mulkerrin, Mulkerrin, & O'Keeffe, 2016), survey research (McCullough, Estes, McCullough, & Rainey, 2007) and semi-structured interviews (Colodny, 2005; Smith-Tamaray, Wilson, & McAllister, 2011).

Results

The five articles used both qualitative and quantitative designs in order to discover what factors might be playing a role in non-compliance of patients with dysphagia recommendations.

Colodny's 2005 research question and resulting article provides the starting point of this review. The question the researcher wanted to answer was how patients with dysphagia justified their non-compliance of SLP feeding recommendations. She completed semi-structured, one-on-one interviews with 63 individuals diagnosed with dysphagia who were identified as being non-compliant for a minimum of two weeks. Participants were all residents of a nursing home in New York City and were independent feeders. During the fifteen minute interviews the researcher asked participants "Would you mind telling me why you did not wish to follow the recommendation for [the particular recommendation]?" Participants' responses were recorded verbatim and then manually coded into the following categories: open denial, dissatisfaction with the product, calculated risk, rationalization, minimization, accommodation, projection, deflection.

The most common response was open denial, meaning that many participants denied having any problems with swallowing. The second most common reason provided was dissatisfaction with the product (e.g. thickened liquids).

One limitation of this study is that the SLP treating/assessing the participants was also the one interviewing them which could cause the participants to alter their answers in order to avoid offending or disappointing her. Another limitation is the manner in which the answers were obtained. Despite the interviewer maintaining a non-confrontational manner and asking open-ended questions, having a face to face discussion about a patient's non-compliance could be stressful for some patients, regardless of who was doing the interviewing.

This study used a suitable research design to answer their question and valid statistical manipulations when appropriate. Their statistical manipulations consisted of verifying inter-rater reliability when coding responses through the use of kappa coefficients. Overall this study discovered compelling evidence of clinical importance. Knowing more about the reasoning patients have for not complying with recommendations is helpful to clinicians attempting to increase rates of compliance. Realizing that denial is a common reason behind non-compliance could help clinicians alter how and what they communicate to their clients.

Kind, Anderson, Hind, Robbins, & Smith (2011) examined how frequently dysphagia recommendations were omitted from hospital discharge communications. This was an observational study looking at retrospective data pertaining to an identified cohort of patients. The researchers identified all hospitalized patients from one facility between 2003-2005 who were diagnosed with either stroke or a hip/pelvis/femur fracture and who also received a billed SLP dysphagia evaluation. All patients were 18 years or older and were later discharged to a subacute care facility. The final sample size was 187 patients. Final SLP hospital chart notes were examined in order to note how many recommendations were made and researchers then organized them into the following categories: Dietary Recommendations and Restrictions, Postural and Compensatory Techniques, Rehabilitative Techniques, Pacing, Sizing, and Procedural Techniques, Medications – Pill Recommendations, Care Provider and Communication Recommendations, and Environment/Other. The patients' discharge reports were then compared to the SLP's final notes in order to find any omissions of recommendations.

Final SLP notes contained on average 5.6 recommendations, while discharge summaries contained an average of 1.4 recommendations. Overall, researchers found that 45% of the discharge summaries omitted all of the dysphagia recommendations made in the final SLP chart note, and another 42% of the discharge summaries omitted at least one but not all of the SLP recommendations.

While alarming to read, this is only one study completed at only one hospital. A limitation of this study is that it is not possible to generalize these results to other hospitals without first examining all of their records. In addition, the researchers did not investigate other ways that recommendations might have been passed along, such as between nurses in the acute and subacute care facilities. It was noted that it was possible some information was passed along this way but that these conversations often do not result in written documentation, making it difficult to track.

Lim, Mulkerrin, Mulkerrin, & O'Keeffe explored the opinions of healthcare professionals and hospital patients without dysphagia in regards to consuming a

thickened liquid diet (2016). Researchers gathered a total of 151 participants for this blocked group randomization trial. One group was comprised of 76 patients with stable health who did not have a diagnosis of dysphagia, and the other group was comprised of 75 healthcare professionals. These groups were then divided in half once more, with one group given Grade 1: Very Mildly Thick Liquid, and another group given Grade 2: Mildly Thick Liquid. Grade 1 is equivalent to naturally thick liquids (e.g. fruit nectar, heavy cream), while Grade 2 liquids are thicker, almost as thick as a thick milkshake (Irish Nutrition and Dietetic Institute, 2009).

Members of the patient group and professional group were randomly assigned to one of two liquid conditions. Everyone was given 200 mL of liquid and asked to drink as much as possible of it. Participants were then asked to trade higher quality of life in exchange for fewer years of life. Participants were given two scenarios: Life A was perfect health, and Life B was perfect health, but they could only consume thickened liquids, like the ones they had sampled earlier. Questions were then posed to the participants in order to determine how many years in life A that they would consider to be equal to 10 years in life B.

Results found that people were willing to reduce an imagined ten year life span by four to six years in order to avoid drinking thickened liquids for those years. There was no significant difference between the healthcare professionals' and patients' responses, using Spearman's rho coefficient to test significance. Results also showed that the groups with the thicker consistency liquid gave up more years of their life and drank less liquid overall.

One major limitation of this study's findings is that they did not recruit patients with dysphagia for this study. While using non-dysphagic patients and healthcare professionals as participants for this study provided dramatic results and could lend support to the idea that thickened liquids contribute to lower quality of life, it does not allow one to claim that this reasoning is responsible for non-compliance. Overall these results are compelling when thinking of clinical practice, but cannot be generalized to patients with dysphagia as they were not a part of this study.

McCullough, Estes, McCullough, & Rainey's 2007 study used a survey research design to investigate registered nurse (RN) compliance with SLP dysphagia recommendations in acute care settings. The researchers distributed 230 surveys to five different acute care hospitals and received 77 completed surveys. The survey asked for demographic information (e.g. years of experience, average number of patients with dysphagia per month) and about feeding, swallowing, and oral hygiene care issues. Respondents were asked to rate statements on a 5-point scale ranging from strongly disagree (1) to strongly agree (5).

Results showed no significant difference between RN compliance with safe feeding techniques, safe swallowing techniques, and proper oral hygiene care techniques. The respondents rated themselves as having a high level of compliance with SLP dysphagia recommendations overall. Results did not show a relationship between RN's years of experience in acute care, age, or number of patients served and total compliance with SLP dysphagia recommendations. The most frequently reported sources of frustration included lack of time to feed patients, too many patients to see, lack of education, and difficulty with feeding patients.

One limitation of this study is that only 34% of the surveys were completed. With such a low response rate, it is possible that the responses received were not representative of all of the nurses/hospitals approached. A larger scale survey could yield different results. Changing the format or length of the survey to encourage greater response rates might also yield different results.

In **2011, Smith-Tamaray, Wilson, & McAllister** examined factors affecting non-compliance rates from the point of view of practicing SLPs in non-metropolitan Australia. Using a semi-structured interview approach, researchers talked to eight SLPs who had previously expressed interest in participating in the study. All of these SLPs worked in multidisciplinary teams. Interviews were administered face to face, took one and a half to two hours and were all completed by one researcher. Responses were audio-recorded so they could be written out verbatim for analysis.

Thematic analysis of interviews was undertaken, consisting of multiple readings of interview transcripts, use of NVivo data management software, manual coding, comparative analysis (between and within transcripts), and mind maps. Two over-arching themes were identified: "Someone misses out" and "You've got to make an impact". The second theme was then broken down into sub-themes and further discussed. The sub-themes included ideas such as the importance of being present, the importance of developing relationships (with both patients and team members), the role of education and knowledge, the feeling of needing to prove your worth, the importance of your role within the team, and compliance with dysphagia management (including compliance of team members).

Copyright @ 2016 , Zelwietro, S.

One of the limitations of this study is that only eight SLPs were interviewed resulting in a small sample size. The data collected from this research is only representative of the eight individuals interviewed. Another limitation is that only SLPs within a team were interviewed, and it would be interesting to hear from other professionals, both within their teams, and those SLPs working outside of a team or hospital setting. These other healthcare professionals might have differing views on dysphagia recommendations and rates of compliance, and in order to resolve any potential problems within a team, one would need the viewpoints of the entire team. Overall this research provides suggestive evidence that might explain why an SLP's recommendations are not always complied with.

Overall the evidence base shows that there are numerous factors that have been identified as playing a role in a patient's decision to be noncompliant. The study designs used were appropriately suited to answer each researcher's question. Of the studies reviewed, the current evidence is compelling. Non-compliance is a prevalent, multi-factorial issue that will affect each patient and clinician on an individual basis.

Discussion

All five research studies approached the question from a different angle, which resulted in gaining information from the point of view of patients with dysphagia, various healthcare professionals, patients without dysphagia, and Speech Language Pathologists themselves.

During Colodny's (2005) study the majority of those interviewed provided two reasons for their non-compliance, with others providing three, demonstrating how non-compliance is frequently multi-factorial. The results found in this study are concerning and provide compelling evidence for clinical practice and to prompt further research in this area, especially in the area of thickened liquids and other modified diet food products. The second highest reason for non-compliance was that individuals disliked both the look and taste of their altered consistencies. If it was possible to create more appetizing meals while using a safe consistency, rates of compliance might increase.

It could be that one of the factors affecting patient non-compliance with dysphagia recommendations is that the patients and their caregivers are unaware of some or even all of the recommendations, due to their omission from discharge reports (Kind, Anderson, Hind, Robbins, & Smith, 2011). This is merely speculation as the results from one hospital cannot be generalized to others, but it is concerning that a large, academic hospital with a dedicated stroke unit had such a high rate of SLP dysphagia omissions. A smaller hospital, or a hospital without such a dedicated unit might be even more likely to omit SLP recommendations.

Another external factor might be that of the caregivers, such as nurses responsible for feeding patients daily. Some results (McCullough, Estes, McCullough, & Rainey, 2007) suggest that there is a difference in perception of job duties, and time constraints, between nurses and SLPs. It could be that while SLPs report non-compliance with recommendations, nurses are reporting lack of education and training in dysphagia treatment. It could be that role clarification between SLPs and nurses (and other healthcare professionals) would improve everyone's knowledge of what is expected and what is feasible.

Something to consider when creating swallowing and feeding recommendations is how realistic these plans are to carry out (Smith-Tamaray, Wilson, & McAllister, 2011). If the nursing staff do not have the time or skill to carry out this recommendation it is not going to help the patient. Recommendations should be practical and straightforward to carry out. This shifts the role of non-compliance from being the sole responsibility of the patient to being a shared responsibility with caregivers and healthcare practitioners.

Clinical Implications

In conclusion, non-compliance is a complex issue, with no simple solution. As a clinician, it is important to consider patient compliance at the individual level and tailor treatment accordingly. Each non-compliant patient will have varying factors influencing their decision. Patients might choose non-compliance to maintain their quality of life, or possibly as a way of denying or resisting this new disability. Certain individuals may use non-compliance as a way of establishing control over a situation in which they otherwise feel powerless. Possible external variables may also exist outside of the patient's and individual caregiver's control. These factors could include treatment personnel lacking sufficient time and/or education to fully comply with all recommendations written in a patient's file. Recommendations may be omitted from medical reports, impacting caregiver's ability to provide an appropriate level of personalized care.

While further research in this area will need to be pursued, these articles highlight concerns that clinicians should consider when working with a non-compliant patient. Research into resolving these issues is limited

but emerging. Research into creating more palatable modified diets, as well as integrated online charting systems, might help to find solutions for such problems as dissatisfaction with food products and omissions of recommendations from discharge reports.

As mentioned previously, some patients will choose non-compliance in order to maintain their quality of life. If the patient is capable of providing informed consent, and is aware of all of the possible risks and outcomes of their behaviour, their choice to remain non-compliant is their right. This is a crucial point for clinicians to remember in order to provide all patients with the highest level of care possible.

References

Colodny, N. (2005). Dysphagic independent feeders' justifications for noncompliance with recommendations by a speech-language pathologist, *American Journal of Speech-Language Pathology, 14*, 61-70.

Irish Nutrition and Dietetic Institute. (2009). Irish consistency descriptors for modified fluids and food: Consensus document, pdf provided by Irish Association of Speech and Language Therapists.

Jackson, L. D., Little, J., Kung, E., Williams, E. M., Siemiatkowska, K., & Plowman, S. (2008). Safe medication swallowing in dysphagia: A collaborative improvement project, *Improving Care at the Front Lines, Healthcare Quarterly (Special Issue), 11*, 110-116.

Kaizer, F., Spiridigliozzi, A-M., & Hunt, M. R. (2012). Promoting shared decision-making in rehabilitation: Development of a framework for situations when patients with dysphagia refuse diet modification recommended by the treating team, *Dysphagia, 27,* 81-87. Doi: 10.1007/s00455-011-9341-5.

Kind, A., Anderson, P., Hind, J., Robbins, J., & Smith, M. (2011). Omission of dysphagia therapies in hospital discharge communications, *Dysphagia, 26,* 49-61. Doi: 10.1007/s00455-009-9266-4.

Lim, D. J. H., Mulkerrin, S. M., Mulkerrin, E. C., & O'Keeffe, S. T. (2016). A randomised trial of the effect of different fluid consistencies used in the management of dysphagia on quality of life: a time trade-off study, *Age and Ageing, 0*, 1-4. Doi: 10.1093/ageing/afv194.

McCullough, K. C., Estes, J. L., McCullough, G. H., & Rainey, J. (2007). RN compliance with SLP dysphagia recommendations in acute care, *Topics in Geriatric Rehabilitation, 23* (4), 330-340.

Smith-Tamaray, M., Wilson, L., & McAllister, L. (2011). Factors affecting dysphagia management and compliance with recommendations in non-metropolitan healthcare settings, *International Journal of Speech-Language Pathology, 13*(3), 268-279.